

Let's Talk About...

As Death Approaches: Changes You May See In Your Child

Death comes differently for every person, and your child's death will be unique. However, there are natural and expected changes that happen as the body's systems fail. You can prepare for these changes now and decide on ways to provide care and comfort.

It may also help to know that **most children stay comfortable with medicines that relieve pain and anxiety.** The doctor may adjust these medicines often, but increasing doses won't shorten your child's life.

How will my child's sleep patterns change?

Over time, your child will sleep more and more. The sleep may seem deeper, and it may be hard to wake your child. This change signals the body's metabolism is slowing.

To help your child:

- **Notice if there are times when your child is more alert.** Plan visits and activities for these times.
- **Stay close to your child,** even if your child is asleep or can't talk. Your presence is comforting.
- **Talk, read, or sing quietly.** Your child may hear your voice and find it soothing.
- **Play your child's favorite music.**
- **Hold your child's hand, stroke their hair, or rub lotion on their hands.** If your child withdraws, remember that this is simply part of the dying process, not a rejection. Your caring touch can comfort your child and express your connection.



How will my child's skin change?

Your child's hands, feet, and limbs may become cool to the touch, and their skin may be splotchy, pale grey, or purple. It may be darker on the underside of the body. These changes are signs that your child's circulation is slowing down.

To comfort your child:

- **Use blankets, socks, and slippers.** These may help prevent your child from feeling cold.
- **Avoid electric blankets or heating pads.** Because circulation is slow, your child's skin can easily burn.
- **Don't insist that your child use blankets.** Even though their skin feels cool, your child may feel hot and want to kick off the blankets.

How will my child's appetite and ability to eat and drink change?

Your child may not need or want much food or liquid. This is a sign that the body is gradually shutting down. Eating and drinking aren't essential.

You may talk to your child's care team about stopping any hydration and nutrition through a tube. Since the stomach and intestines stop working well, continuing can be uncomfortable for your child.

To comfort your child:

- **Offer their favorite foods and drinks and allow them to choose what they might enjoy.** Don't insist that they take food or fluids.
- **Give small sips of fluid** that can be sucked from a small oral sponge or a moist washcloth.
- **Gently wipe your child's lips** with a cool, damp washcloth.
- **Use an oral moisturizer** on your child's teeth and gums.
- **Apply a water-based lubricant (like K-Y jelly) on dry lips and nostrils** if your child is on oxygen therapy. Otherwise, you can apply small amounts of lip balm or petroleum jelly to ease dryness.

How will my child's bladder and bowel change?

Your child may have fewer bowel movements and won't need to urinate (pee) as often. The urine will be darker and have a stronger smell. This is normal.

As your child takes in less fluid and food, there's less waste. Their kidneys may also be shutting down. It's common for your child to lose bladder and bowel control. Use disposable diapers and bed pads if you need to.

Will my child have seizures?

If your child has a brain tumor or metabolic problem, they may start having seizures. A child with a seizure disorder may also have seizures more often at the end of life. In this case, talk to your child's caregivers about adjusting their medicine.

If your child has a seizure, try to stay calm. Turn them to their side, and don't try to put anything into their mouth. Seizures can be hard to watch, but your child doesn't usually suffer and won't remember it.

How will my child's behavior change?

Your child may become confused about time, place, and people. Some children have trouble recognizing close friends and family members. Your child may also be restless or upset. They may pick at the sheets, change positions a lot, or see things that aren't there.

This happens because your child has less oxygen going to the brain, less fluid in the body, and lower kidney function. Medicines can also cause changes.

To help your child:

- **Tell them you love them often and as long as it comforts them.** Speak in a gentle, reassuring way.
- **Don't insist on correcting your child or try to argue or reason with them.**
- **Sit next to the bed or cuddle with your child.** Your presence can help soothe your child and remind them where they are.

What happens when my child is close to dying?

As your child is close to death, you may notice the following changes:

- **Louder breathing.** Your child's breathing may be louder, more ragged, or gurgling. It may sound like snoring. This happens when saliva is more dry and thick and the throat muscles are more relaxed. It's not distressing or painful to your child.
- **Pale, bluish lips and nail beds.** This is a further sign of slowing circulation.
- **Half-open eyes and mouth.** Your child's eyes remain partly open and look glassy. Their mouth may fall open.
- **Stop-and-start breathing.** Your child's breathing may change, and they may have long periods between breaths. This interrupted and irregular breathing is common in the final hours of life.

How can I comfort my child when death is near?

In your child's final hours, continue to comfort them in ways that feel right to you. Raise your child's head and body with pillows as it becomes harder for them to breathe. Turning your child partly to the side may allow secretions (mucus in the lungs) to drain.

Familiar routines, such as sitting close, listening to music or a video, talking, singing a lullaby, reading a favorite story, and cuddling may be especially comforting now to you and your child.

What can I expect when my child dies?

When your child stops breathing and the heart stops, you may hear a final long sigh or gasp of breath. Your child may also pass urine or stool (poop) at this moment of death.

After your child's death, you may spend time at the bedside with your family. Take as much time as you need to hold and talk to your child, bathe and dress your child, or do religious or spiritual rituals that are meaningful to your family. Your child's healthcare providers will honor your wishes and offer privacy.



Caring for yourself

Taking care of your child may come naturally to you, but taking care of yourself might not. You can easily become exhausted, which makes it harder to care for your child in the ways you want to. Here are some tips to help you save your energy:

- **Schedule breaks.** Have someone take your place at the bedside, even for just 15 minutes, if you don't want to leave your child alone.
- **Get outside every day, if only for a brief walk.** A few minutes of fresh air can soothe you and help you focus on yourself for a short time.
- **Get enough sleep and rest.** You may need to leave the hospital or your home for a few hours so you can sleep without any interruptions.
- **Eat regularly and focus on healthy foods.** You need good fuel during this stressful time so you can be present for your child and other family members.
- **Find a time and place to cry, complain, or shout.** It's important to express the intense feelings you may be holding inside. An understanding listener can help.
- **Be gentle with yourself.** The end of life will come in its own time and in its own way. You're not in control, but you can better comfort your child by caring for yourself.

